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## ***Shuster Reintroduces Legislation to Help Children Receive Life Saving Medical Treatment***

Washington, D.C. – Congressman Bill Shuster, is pleased to announce that he has reintroduced “Nino’s Act,” legislation that seeks to provide continuous medical care to children who are transitioning out of research studies with the National Institutes of Health (NIH).

In many instances, children experiencing rare or life threatening illnesses take part in medical research studies through the NIH to gain access to new and emerging medications and therapies. Very often, the medications used by NIH are experimental and have either not been approved by the Food and Drug Administration or have not been cleared to treat a specific illness. When children leave an NIH study, they are at risk of losing access to these life saving therapies because their private insurance won’t cover them.

“The NIH does ground breaking work to evaluate new medical treatments for juvenile diseases,” Shuster said. “For many children suffering from rare diseases, these experimental trials are the only way to take advantage of cutting-edge treatments that would otherwise be out of their reach.”

“Children who respond positively to these therapies should not have their hopes dashed and their health suffer once they leave the NIH system,” Shuster added. “Medicaid should be there to fill the gap and extend life saving medical treatment.”

Shuster’s legislation seeks to close this gap in care by allowing children transitioning out of NIH medical studies to continue to receive successful medical treatments through Medicaid if private insurance refuses to cover the cost.

Nino Todaro of Newville, Pennsylvania is the namesake of Shuster’s legislation and an example of why this legislation is necessary. In 2003, Nino was selected to take part in an NIH study for Undifferentiated Auto Inflammatory Periodic Fever Syndrome. The treatment received through the NIH allowed Nino to live a normal life.

However, when Nino exited the study, his parent’s private insurance would not cover the life-saving treatment he received in the NIH study. The Todaro family’s insurance carrier relented only after a long and drawn-out battle by headed by Nino’s mother, Lori.

“No family should have to endure what Nino and his family went through,” Shuster added. “Sick children should not fall through the gaps of our healthcare system.”

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